Workshop C: State Laws, Regulations, and Policies Affecting Prevention of Perinatal HIV Transmission — Kathy Rauch, chair

Goal: To inform and discuss ways in which policy at the national, state, and local levels can impact prevention of perinatal HIV transmission

Objectives

- Discuss ways in which state laws, regulations, and policies can impact perinatal HIV transmission
- Discuss issues and lessons learned from the recent Connecticut experience with a new state law for perinatal HIV screening
- Discuss potential Medicaid and other policy interventions to prevent perinatal HIV

Continuum of Interventions

Law	o **Regulation**	o **Policy**
Least changeable	More flexible	Most changeable and flexible
May not be what public health wants		More predictable by public health
Highly enforceable	Somewhat enforceable	Not very enforceable. (To improve enforceability, approach licensing boards, put policy language in contracts.)

Legal and Ethical Analysis — Zita Lazzarini, University of Connecticut Health Center (UCHC)

UCHC analyzed legal issues and summarized a national survey of state laws.

Purpose

- Compare state laws and policies with 1995 Public Health Service (PHS) recommendations.
- Analyze legal and ethical issues.
- Identify barriers to 1998 Institute of Medicine (IOM) recommendations.

Method. Surveyed state epidemiologists in all states and territories.

Response. 49 states and Guam responded.

Conclusions

- States moved quickly to implement PHS guidelines (47 states had a regulation, law, or policy).
- Majority have policies (45); fewer have laws/regulations (27).
- Most efforts rely on education, counseling, and consensual testing.
- Most had policies/guidelines or laws to cover testing pregnant women (45 policies; 25 laws).
- Some had policies/guidelines or laws to cover treatment of pregnant women (35 had policies; 7 had laws/regulations).
- Fewer states have laws or policies regarding newborns (26).
- Few states incorporate mandatory or coercive actions into testing provisions (0 mandate testing pregnant women; 3 mandate testing newborns).
- Over half the states have criminal sanctions for knowing or intentional exposure (29); no state has applied laws to perinatal transmission.
- A few states exempt pregnancy from the modes of exposure for purpose of knowing exposure laws.
- Washington Department of Health determined that the law would not apply to perinatal transmission unless the mother intended to harm the child.
- The Institute of Medicine (IOM) recommends "universal HIV testing, with patient notification, as a routine component of prenatal care."
- Only 5 states currently have routine "opt out" provisions that most closely reflect the IOM recommendations.
- Changes in state laws would have to occur to implement IOM recommendations that could conflict with the states' own pretest counseling and informed consent laws.
- Potential barriers include: 40 states require voluntary testing based on informed consent (35 by law; 5 by policy).
- 8 states have "opt in" provisions for testing (very close to informed consent requirement).
- 21 states specifically mandate pretest counseling by law.

Discussion

- Largely voluntary approaches have cut new pediatric HIV cases by 66%.
- Voluntary HIV testing is the current norm.
- Although there may be public health justification, coercive policies can deter testing and reduce trust.
- Detailing what providers must discuss in the language of the law can intimidate providers.
- Don't let policy changes get ahead of scientific evidence.
- States hesitate to go back to their legislatures when the current law has been successful.
- Revised legislation could be awkward to implement.
- Some fear that legislatures may take the opportunity to open up broader discussion of mandatory testing, at least for certain populations (e.g., healthcare workers exposed by needlestick), leading to incremental changes.

Connecticut Experience—Richard Melchreit, State of Connecticut

- In 1992 (predating Pediatric AIDS Clinical Trials Group 076), Connecticut passed a law that simply stated that obstetricians must offer the test to pregnant women.
- In the 1999 session, the Connecticut legislature began a process to revise the law, because some women were being missed as demonstrated by anecdote and evaluation data.
- The session ended in early June without action on the issue. During a special session later that month, the new law was passed as part of an omnibus health and human services bill.

Details of New Law

- Providers must counsel and offer HIV testing to pregnant women at enrollment for prenatal care and during the third trimester.
- If the woman is not tested prior to delivery, she is to be tested at delivery, unless she refuses and signs a declination form.
- If the woman does not get tested at delivery, then the baby must be tested except in the case of religious exemptions.
- When testing of the newborn occurs, the mother must be informed of results within 48 hours of delivery or before leaving the hospital, whichever comes first.
- The Connecticut Hospital Association petitioned federal court for a temporary restraining order to prevent the law from going into effect on October 1, 1999. That petition was denied, so the law is in effect. However, a lawsuit is going forward. The plaintiff in the lawsuit is arguing that the testing called for by the law is an unconstitutional search and seizure.

Issues

- Watch what laws other states pass because legislators talk to each other.
- Simplicity in legislative language is helpful to all affected.
- Stakeholders in any new law will be seeking information. Organizations in positions to provide technical assistance should be prepared to be proactive.
- Don't take assertions at face value without the backup of reliable data.
- Reauthorization of the Ryan White CARE coming up this year may be an appropriate vehicle for continued support of perinatal HIV prevention.

Medicaid and Other Policy Interventions — Kathy Rauch, Centers for Disease Control and Prevention

Public health officials are more likely than anyone else to convince Medicaid to adopt policies relating to HIV prevention.

Extent of Medicaid Coverage

- 38% of U.S. births during 1996 were covered by Medicaid.
- For women 15 to 44 years of age, who delivered a live infant between 1991 and 1995, 62.0% of non-Hispanic black women, 56.3% of Hispanic women, and 23.0% of non-

Hispanic white women were covered by Medicaid for their most recent delivery.

- Medicaid is the largest source of HIV/AIDS financing in the United States, with estimates of $3.9 billion of HIV/AIDS expenditures; this is more than twice the $1.4 billion under the Ryan White CARE Act (RWCA).
- According to the Health Care Financing Administration (HCFA), Medicaid serves more than 50% of persons living with AIDS and up to 90% of all children with AIDS.

Encourage State Medicaid Agencies to

- Make perinatal HIV prevention a priority in their planning for both fee-for-service and managed care.
- Ensure HIV prevention and care services are in the capitation rate or paid through direct billing.
- Advise Medicaid providers of HIV prevention policies and available resources.
- Include specific language on HIV benefits and services in
    - Requests for Proposals (RFPs)
    - Managed care contracts (a place that policy can be given some "teeth")
    - Primary care case manager (PCCM) letters or contracts
- Include prenatal HIV testing performance measures in managed care contracts, especially in high-incidence areas and areas with low Health Plan Employer Data and Information Set (HEDIS) scores on prenatal care.
- Identify testing performance as a performance improvement project.
- Investigate performance in external quality reviews.
- Share performance results with public health.
- Have health plans work with public health to improve performance.
- Use financial incentives with health plans to achieve and maintain performance in testing pregnant women and delivery of prenatal care (could be withheld and then awarded if the plan achieves a stated level of performance, or could be a reward).
- Require or encourage health plans to
    - have clinical policies to facilitate universal HIV testing of pregnant women, and
    - collaborate with public health to establish effective clinical policies and to share educational programs.

Explore with the Medicaid Agency

- Requiring or encouraging participating hospitals to have
    - clinical policies to facilitate universal HIV testing of pregnant women; and
    - testing protocols, policies, and antiretroviral therapy available in labor and delivery units.
- Providing financial incentives to PCCM providers to test and counsel women of childbearing age in areas of high HIV prevalence
- Determining eligibility for incarcerated women prior to release, to ensure continuity of care